

# Caritas Research

Issue#11 5th Anniversary Issue 2008

## The Little Research Centre that Could

Can a small research centre function effectively within a large institution? Given the current trend to “bigger is better” – an approach characterized by amalgamating centres run by individual institutions – the expected answer might be “no”. But for Dr. Fred MacDonald, Clinical Director of the Caritas Research Centre, the answer is a resounding “yes.”

“Healthcare institutions all over North America are being drawn in into ever larger networks,” says Dr. MacDonald. “To be sure, there can be real benefits in larger networks in terms of efficiency and effectiveness. But when it comes to encouraging research at a grass-roots level, there are advantages to keeping things small. We’ve demonstrated this at the Caritas Research Centre. You can do good work by functioning independently and keeping control.”

Indeed. Now, as the Caritas Research Centre celebrates its fifth anniversary, it has developed into a “one-stop shop” for anyone planning to do research in Caritas institutions. The Centre has handled the



*Caritas Research Centre: Jo Anne Nettleton, Director of Education & Research; Dr. Fred MacDonald, Clinical Director; Mary-Ann Clarke, Administrator*

administration of more than 550 projects representing more than 360 researchers and distributed more than \$1.3 million per year in research funding. It all adds up to an impressive track record for a small centre run by part-time staff.

But numbers alone don't tell the story of the Caritas Research Centre, says Sheli Murphy, Vice President of Operations, Misericordia Community Hospital, and Chief Nursing Officer and Executive Lead for Research, Caritas Health Group. “Research is the cornerstone for responsive health care. For

Caritas, it is an essential part of fulfilling our mission of *Healing the Body, Enriching the Mind, Nurturing the Soul*.

“Through research, and more importantly the knowledge and understanding derived from research, we contribute to the improvement of patient and resident care and make a real difference in people's lives and in our practice.”

### A look back

To understand the beginning of the research centre we have to go back to 1969 – the year Dr. Fred MacDonald did his first clinical study for a

### Congratulations to the Caritas Research Centre on its fifth birthday!

As health researchers and caregivers, we at Caritas are driven to bring about healing through quality care that is grounded in knowledge, evidence-based learning and understanding.

With wisdom and determination, the Caritas Research Centre has brought its passion for service and the power of creativity, inquiry and intellect together, and to the forefront in our organization, encouraging all of Caritas members to be leaders in compassionate care and innovative in their services to those in need.

*Patrick Dumelie  
President*

pharmaceutical company. No investigational research of pharmaceutical products was being done at the time, yet there was a demand from companies for this type of work. Dr. MacDonald saw the opportunity, and began studies at the Edmonton General.

Because there was no ethics board at the time, an ad-hoc ethics committee had to be set up. Administration consisted of little more than a secretary who recorded the cases that came in for approval. It was much the same at the other

### Celebrating five years of achievements

The Caritas Research Centre evokes the pioneering spirit and resourcefulness of our founders, the Sisters of Charity (Grey Nuns) and the Misericordia Sisters, who constantly sought new ways to foster hope and healing among those in need.

Thank you for promoting best practices and challenging our team members to seek answers, to gather evidence, and to pioneer new approaches to improve the quality of care we provide.

*Sheli Murphy  
Chief Nursing Officer and  
Executive Lead of Research*

hospitals. The result was the establishment of about five research boards in Edmonton, all operating independently.

This was a major headache for anyone who wanted to do clinical research in more than one institution. So in 1990, the University of Alberta, Capital Health and Caritas came together and formed a tripartite research ethics board to streamline approvals.

While the Health Research Ethics Board made things easier for researchers, Dr. MacDonald felt it was not enough. He identified a need for a resource that could help people transform their ideas into viable research projects. That insight was the genesis of the idea for the Caritas Research Centre. In 2001, a strategic plan for the Centre was developed and presented to the Caritas board. While support for the concept was strong, the stumbling block was money.

Again, Dr. MacDonald had a solution – pool the money from individual research accounts and use the interest to run the office. In return, the office would provide researchers with all services related to legal advice, ethics approval and administrative support. Another source of funding was the overhead built

into clinical research projects. Dr. MacDonald lobbied for a share of this money for research carried out at Caritas institutions. Despite initial resistance, all parties reached an agreement.

“We have a great partnership with the University of Alberta and Capital Health,” says Mary-Ann Clarkes, Administrator, Caritas Research Centre. “The Centre also represents Caritas on all health research boards and initiatives in the region. It's vital to our credibility that Caritas speak with one strong voice to our partners, funding agencies and industry.”

Another innovative funding mechanism introduced by the Centre is a 10% refund of the amount of the research grant back to the researcher on completion of the project. This money has been used by individual researchers for a wide range of purposes including seed funding for new research projects and staff training.

At the time, the concept of a board administering research funds and using the interest and overhead was new. Initially, there was resistance. But with time, people have come to appreciate the need for the Centre to build up equity so that it could staff, purchase supplies and sponsor workshops.

### Comprehensive support for research

The Centre plays a pivotal role in moving research forward in the Caritas organization. One of its functions is providing continuing

**Thank you! (Caritas Research Centre, 2003 to 2008)**  
Dr. Fred MacDonald  
Anne Willans  
Mary Swedberg  
Angeline Higgins  
Jo Ann Nettleton  
Donna Wilson  
Leslie Crawford  
Mary-Ann Clarkes

## Focus on ethics

Clinical research cannot proceed without ethics approval from the Health Research Ethics Board, a joint committee of the University of Alberta, Capital Health, and Caritas. Recognizing Caritas' unique position as a faith-based healthcare provider, the Caritas Research Centre negotiated a “right of second review” for research projects that may conflict with the Caritas mission. In these cases there have been two in the past five years a special ethics group is convened to look at the issue and indicate to the researcher whether it is within the scope of the Catholic Hospitals Association guidelines for research.

education to staff and physicians who are interested in developing their research competencies. Workshops are offered on a variety of topics including ethics approvals, research methods, and how to increase the chances of getting published. The Centre also sponsors and organizes the annual Research Day, which showcases research undertaken at Caritas institutions. Each year, the Research Day brings in a distinguished speaker on a topic of special interest. The workshops and the Research Day are open to staff from all institutions.

Caritas Vice-President Sheli Murphy notes that another key function of the Centre is helping staff get potential research projects off the ground. “Caritas is committed to offering a fulfilling workplace environment that inspires learning and where inquisitive and critical thinking is encouraged. The questions asked by our physicians, nurses, therapists and lab technicians in their daily practice are vital to our efforts. When those questions are formalized into research and investigated, amazing things can happen. The Centre provides a 'soft place' to begin asking the questions.”

Bring on the questions, says Dr. MacDonald. “I always say: If you've got a good question, you've got a good research project.”

But the question is only the starting point. A research project requires much more to be successful: developing the research question so that

outcomes can be reported, determining the best way to carry out the research, patient safety and privacy issues, funding, and ethics and administrative approval. All of these can be daunting to a first-timer. The Caritas Research Centre helps with all these aspects.

“The Centre has really nurtured researchers – young people starting out as well as clinicians who are fairly mature in their careers,” says Dr. Johan Wolfaardt, co-Director of the Institute of Reconstructive Sciences in Medicine (iRSM, formerly COMPRU). “It is often exceedingly difficult for aspiring researchers to develop anything on their own. The Centre provides much-needed assistance.”

And it's more than advice and moral support. The Centre administers the Caritas Research Fund, which awards about \$60,000 in research support every year. The maximum grant is \$5000. Although the amounts are small compared to most research funding, sometimes this is all that is needed to run a small study. There are very few agencies that support research on a small scale, and for these cases the Caritas Research Fund fills an important gap.

“It's vital to have a source of funds to seed research,” notes Dr. Wolfaardt. “Seed funding is hard to come by in today's highly research-intensive environments. Small projects can be considered trivial. But I believe that the greater the base, the higher the pyramid. The Caritas Research Fund builds the base.”

In addition to starting new projects, researchers have used Caritas funding to leverage substantial

additional funding from provincial, national and even international agencies. The support from Caritas has allowed these researchers to demonstrate that they've got more than an idea that their project has been reviewed and approved, and has solid backing.

“It is gratifying to watch an idea grow from the application to approval, to being funded, and then move through completion, publication and other translation to practice initiatives,” adds the Centre's Mary-Ann Clarkes. “I'm excited to see the course of future practice affected by Caritas researchers.”

### **Moving research forward**

In the past five years, the Caritas Research Centre has made great strides in educating healthcare professionals about research, encouraging them to take on projects, and providing seed funding. One key growth area has been the increase in research undertaken by nurses and other allied health professionals. Five years ago, most researchers were physicians. This is not the case anymore. And Dr. MacDonald sees the potential for attracting even more people from all disciplines to research.

“Looking back on my career, the Caritas Research Centre is one of my big accomplishments. And yet, we have barely scratched the surface. There's so much more we could do to move research forward. Right now, my plan is to visit departments at all three Caritas institutions to give them a 'fifth anniversary special' a talk about what has been accomplished and how much more we could do.

“Research is a way to reach out beyond our daily experience and work to make things better. I'm proud to have played a part in creating an environment that makes it easier for people to do this.”

## *Thank you to the Caritas Research Centre Steering Committee:*

Shannon Daly, Dr. Andrew Greenshaw, Christine Lamash, Karen MacMillan, Brenda Madsen, Sheila McNary, Anna Marie Moscardelli, Sheli Murphy, Vikki Newman, Fran Ross, Kim Scherr, Dr. Marcelo Shibata, Dr. David Shragge, Dr. Johan Wolfaardt, Dr. Harry Zirk. Non-voting Members: Richard Fraser, Karen Noga, Donna Wilson

## *Thank you to the CRC Ad-Hoc Committee:*

Richard Fraser, Vikki Newman, Christine Lamash, Darlene Blischak, Carmen Carvajal

# Caritas Research Day 2008/ Caritas Research Dinner



*Dr. Gerald T. Gau*

“Research Day” has become an annual event at Caritas, and this year marked the 4th year that this event had taken place at the Grey Nuns Community Hospital, with attendance for the day exceeding 170 participants. The full day of activities included formal presentations, poster presentations, a luncheon and a panel discussion.

As a precursor to this year's Research Day events, a Research Dinner was held at the University of Alberta Faculty Club and attended by both invited and sponsoring guests. Speakers included Patrick Dumelie and Sheli Murphy, with a dinner reflection offered by Gordon Self. A special lecture was also provided by Colleen Gau, RN, PhD entitled “*The Effect of Tight Corseting on the Respiratory Function of Women [and Men]*”.



*Clockwise from top left: Patrick Dumeli speaks at the Caritas Research Dinner; the Amati Trio at the Caritas Research Dinner; Sheli Murphy presents a Caritas Inukshuk to Colleen Gau at the Caritas Research Dinner.*

Sheli Murphy and Dr. Fred MacDonald opened the proceedings for Research Day, and the initial lecture was provided by Dr. Gerald Gau, a Professor of Medicine at the Mayo Medical School in Rochester, Minnesota, and Consultant with the Department of Internal Medicine, Division of Cardiovascular Diseases at the Mayo Clinic. Dr. Gau began his medical training at the University of Alberta, and completed his internship at the Edmonton General Hospital.

The theme for Research Day was “Chronic Disease”, and we were fortunate enough to have speakers from various fields of interest speak to the topic. Lectures ranged from specific chronic disease process and its management, to the impact of chronic disease on health services utilization. The

day also provided an opportunity for Caritas researchers to present posters of studies that involve or are taking place at Caritas. A Panel made up by Dr. Vince Yakishyn, Dr. Gerald T. Gau, Dr. Manohara Senaratne and Sheila Dalessio ended the Research Day event with a lively discussion.



*Poster presentations at Research Day*



*Dr. Louis P. Mousseau  
1908-1962*

Dr. Gau's lecture was sponsored by the Mousseau Memorial Lectureship Fund, a fund in place to support continuing education.

Dr. Louis P. Mousseau performed the first autogenous vein graft in Canada, one of his many noted contributions, and was recently honored as one of the "Physicians of the Century", a designation afforded to 100 physicians to celebrate 100 years of organized medicine in Alberta, a 1905 to 2005 Centennial Project supported by the College of Physicians and Surgeons of Alberta and the Alberta Medical Association.

**A special "Thank You" to all of the people who assisted in making Research Days a success!**

**Lecture Presentations:** Dr. Gerald T. Gau, Dr. Jacques Romney, Dr. Muzaffar Siddiqui, Suzanne Hare, MSc(C), RD; Dianne Drummond, MSc,RD; Mike Stickland, PhD; Tina Jourdain, RRT; Mark Haykowski, PhD; Dr. Phillip Jacobs; Anderson Chuck, PhD(C); Stuart Cleary,

MS,CCC-SLPR-SLP; Sonja Wheeler, RRT; Donna Wilson, RN,PhD; Dr. Vince Yakishyn.

**Introductions:** Sheli Murphy; Dr. Fred MacDonald.

**Room Facilitators:** Louise Kashuba; Darlene Blischak and Jo Ann Nettleton.

**Registration:** Bronia Helik

# iRSM (formerly COMPRU) Receives Special Designation for Research

Institute for Reconstructive Sciences in Medicine (iRSM) among the first health care units to be granted ISO 9000 status globally



In November, 2007 iRSM received approval to extend the scope of its quality systems ISO 9000 designation to include research.

“This is a big step for iRSM” says Dr. Diana Shaw, iRSM's Director of Business Development. “Nobody else has this designation. It has enlisted a positive response from the researchers working with iRSM and other individuals looking at setting up similar procedures.”

Applying for ISO (International Organization for Standardization) designation is voluntary and demonstrates an organization's commitment to quality in research processes. In 1997, iRSM was one of the first publicly funded healthcare programs in Canada to register an ISO 9000 quality standard for clinical activity.

Dr. Shaw explains that ISO is a quality management system. “ISO 9000 Research

compliance will offer us a way of following a project and ensuring all appropriate documents and required approvals are in place prior to initiating research. In terms of research, it offers us a way of ensuring management of research processes, measuring increased activity, publications and collaborations. It structures and streamlines processes for tracking and managing numerous finely detailed and varied projects.”

iRSM has more than 70 local and international research projects underway related to the three priority research themes for iRSM of modeling and analysis, biomechanical engineering and treatment outcomes.

Using a unique integration of clinical and research activities iRSM focuses on rehabilitation of patients who have either missing or absent structures of the head and neck resulting from birth defects, cancer, infections and trauma. The work of iRSM combines a wide range of surgical services and implantable devices, as well as facial and oral prostheses to rehabilitate patients who require replacement of absent or lost tissue.

*For further information, contact Dr. Shaw at [Diana.Shaw@capitalhealth.ca](mailto:Diana.Shaw@capitalhealth.ca)*

## Caritas Libraries



Wondering where to find out about Library services at Caritas? Check out the Caritas Libraries intranet website at

[www.intranet2.cha.ab.ca/caritaslibraries/](http://www.intranet2.cha.ab.ca/caritaslibraries/)

for information on: staff and the information services that they provide; library locations and hours; print and electronic collections and how to access them; and much, much more...

Caritas Learning Resources (Library and Audio Visual Services) congratulates the Caritas Research Centre as it celebrates its 5th anniversary coordinating ethical, clinical research.

# Soft Palate Cancer Treatment: Translation of Research into Clinical practice at iRSM

*Words are, of course, the most powerful drug used by mankind. - Rudyard Kipling*

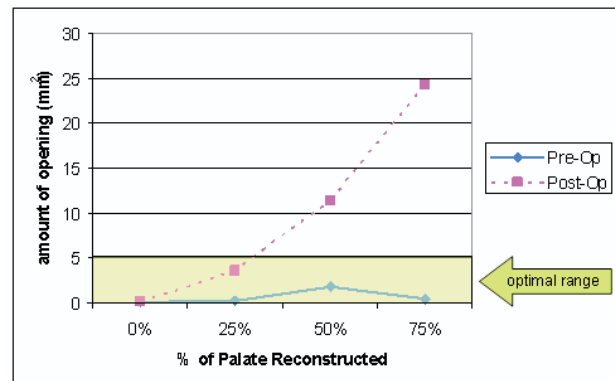
Communication with others forms the basis for who we are, who we are perceived to be, and how we function socially, at work, and in our home. Many times, people underestimate what it takes to produce speech it just seems like a natural thing to do. However, the complexity of producing speech is remarkable. Speaking requires the coordination of many different muscles in the mouth, throat, and chest. When one of these muscle systems does not work properly, natural sounding speech is compromised. Nowhere else is this more obvious than when the muscles of the soft palate are affected by a congenital condition, trauma, surgery or radiation therapy.

The soft palate is attached to the hard palate (that is, the roof of the mouth). While the hard palate is made of bone, the soft palate is made of muscles. The muscles in the soft palate contract rapidly during speech. By doing so, the muscles prevent the inappropriate flow of sound through the nose when speaking. When the muscles of the soft palate are not able to do their job, the quality (or resonance) of the speech signal can change. When this is the case, people will describe their speech as sounding nasal, as being misunderstood, as being quiet, and very tiring to produce. These changes can be very distressing to an individual.

Over the past 8 years, we have been studying the relationship between speech outcomes and different types of surgeries and prosthetic interventions. We have learned a great deal and have continually refined our procedures so that we obtain the best possible speech outcomes. Our research has led us to abandon certain surgical techniques and prostheses, and to adopt others. We would like to share with you what we have learned about intervention for the soft palate during our 8 year journey.

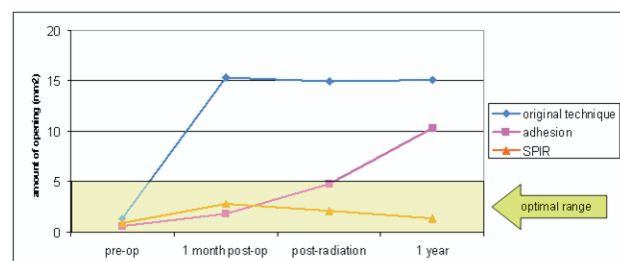
In 2003, we reported on patients that we had been treating between 1998 and 2001 with surgery to reconstruct the soft palate. We learned that patients

who needed bigger reconstructions of the soft palate were not benefiting as much as we would have liked from the surgical reconstructive procedure at that time.



The graph above shows that patients who had 50% or more of their soft palate reconstructed were not able to achieve normal closure between the oral and nasal cavities after they had surgery. (Laryngoscope 2003; 113(5): 897-904).

Between 2001 and 2006, the head and neck surgeons at the University of Alberta Hospital (Dr. Seikaly and Dr. Harris) who are part of our team used this information to revise reconstructive surgery for patients who had larger defects of the palate. They began with a procedure known as an adhesion, which did not withstand radiation therapy. And so the surgeons developed a procedure called the Soft Palate Insufficiency Repair (SPIR).



The SPIR is showing very promising results for restoring normal nasal resonance in patients. This

research has recently been accepted for publication in Head & Neck. The graph below shows the speech results for each type of reconstruction that has been used over the past 8 years. Patients who had the SPIR procedure remain within a normal range of soft palate closure at all points in time, unlike patients in the other 2 groups. Dr. Seikaly and Dr. Harris no longer use the original technique or the adhesion to reconstruct large defects of the soft palate.

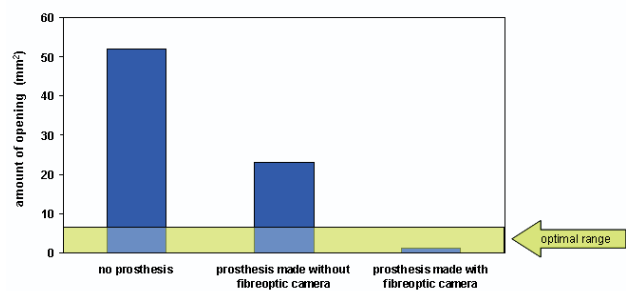
For patients who had problems with nasal resonance after reconstruction with the original technique or the adhesion, a prosthesis was created to help them achieve separation between the oral and nasal cavities.



This prosthesis is worn inside the mouth and has an extension that travels back across the soft palate and up towards the nasal cavity. In the past, we made these prostheses by relying on “wax molds” that were taken while a patient was speaking. This technique of making prostheses felt like trying to swing a bat at an object in a dark room. Thus, we started using some advanced technologies to help with the process.



By using flexible fiberoptic video nasendoscopy (a small camera that is inserted through the nose so that we can see the back of the nasal cavity and throat), we were able to make prostheses that worked better for our patients.



In the graph above, you can see that we achieved better speech results when we used the fiberoptic nasendoscopy. We published these findings in the International Journal of Prosthodontics 2006; 19(4): 383-388.

There are still some unanswered questions that we are aiming to solve when it comes to treatment for soft palate defects. We are currently working with the Memorial Sloan Kettering Cancer Center in New York to understand how prosthetic treatment like that just described above compares to our surgical treatments for large soft palate defects. By continually assessing what we are doing clinically through our research program, we will be able to continue to improve speech outcomes for our patients.

# Ethics Applications with HREB and the New HERO Online System

The University of Alberta is moving to a new web-based ethics system Human Ethics Research Online or HERO. [Additional information about HERO is available at [www.ais.ualberta.ca/hero.cfm](http://www.ais.ualberta.ca/hero.cfm)] HERO will automate the ethics review processes for human subject research through an internet application form which will be routed electronically for required reviews and approvals. Researchers will be able to collaborate on application development on-campus and off, save draft applications, bank their ethics applications and SOPs, incorporate material from grant applications and other sources and monitor the approval status of their ethics applications

The Biomedical Panel/Panel A of HREB is part of the pilot implementation and is conducting a staged roll-out, starting with the Department of Medicine and the Department of Pediatrics. The deadline for applications for the 20 June 2008 panel meeting is 6 June 2008. These applications will use the existing paper application forms.

Effective 7 June 2008, all NEW ethics applications (full and delegated review) to the HREB BIOMEDICAL PANEL from ALL researchers (full-time and part-time) with an academic appointment (tenure track, clinical, sessional, adjunct) in the Department of Medicine and the Department of Pediatrics must be prepared and submitted using HERO.

All other Panel A applications, ie a renewal from Family Medicine or an amendment from Ophthalmology, will use existing forms and processes. Training for all other Panel A applicants will be provided in July and August.

In order to use HERO, you must have a valid Campus Computing ID (CCID). All individuals with University appointments have a CCID and password. If you have forgotten or misplaced your CCID, you may verify your ID by checking with the HR team in your department (see below) or by

calling CCID Administration at 492-0400. CCIDs are administered by Academic Information and Communication Technology (AICT). More information about CCIDs is available at <http://helpdesk.ualberta.ca/ccid/>

Individuals from Caritas or Capital Health, who do not have a University of Alberta appointment, may apply for a "Guest" CCID. A Guest CCID must be requested in writing from your home/affiliated University department. (Guest IDs expire after one year but may be renewed.)

- Guests associated with the Department of Medicine should contact the HR unit at 407-7525.
- Guests associate with the Department of Pediatrics should call the HR Manager at 407-1686.
- Study coordinators will be able to prepare ethics applications on behalf of their PIs, if they have a CCID. If a study coordinator is not University staff, s/he will need to apply for a guest CCID from their PI's home department.

HERO information and training sessions exclusively for researchers in the Departments of Medicine and Pediatrics will be held in late May and early June. On-line training materials will be available when HERO goes live on 7 June 2008. Depending on your learning style and comfort with on-line applications you may not need to attend both an information session and a classroom session. If you have any questions or concerns about HERO, the implementation schedule or the training and information sessions, please contact Sharon Campbell, [sharon.campbell@ualberta.ca](mailto:sharon.campbell@ualberta.ca) 407-3131 Department of Medicine or Susan Babcock, [susan.babcock@ualberta.ca](mailto:susan.babcock@ualberta.ca) 492-6561 Research Ethics Office



To register for a session, please contact Kathy Strawson, 492-0459 or [kstrawson@med.ualberta.ca](mailto:kstrawson@med.ualberta.ca) in the HREB Office, 213 Heritage Medical Research Centre.

Session	Date/Time	Location
HERO Information session (1.5 hours) Overview	Wednesday, July 30 10:30 noon	Classroom D
HERO Information session (1.5 hours) Overview	Thursday, August 7 9 am 10:30 am	Classroom D
HERO Information session (1.5 hours) Overview	Tuesday, August 12 1:30 pm 3 pm	Classroom D
HERO Information session (1.5 hours) Overview	Monday, August 18 10:30 noon	Classroom D
HERO Information session (1.5 hours) Overview	Wed, August 27 10:30 - noon	Classroom D
HERO Classroom training (3 hours) Overview & hands-on training	Tuesday, August 12 9 am noon	W. Mackenzie Health Sciences 2F102
HERO Classroom training (3 hours) Overview & hands-on training	Wed, August 13 9 am noon	W. Mackenzie Health Sciences 2F102
HERO Classroom training (3 hours) Overview & hands-on training	Monday, August 18 1 pm 4 pm	W. Mackenzie Health Sciences 2F102
HERO Classroom training (3 hours) Overview & hands-on training	Wed, August 20 9 am - noon	W. Mackenzie Health Sciences

## Compassion Fatigue: The Experience of Nurses

“I haven't enough feeling left for human beings to do anything for them out of pity.”  
- Querry, from Graham Greene's *A Burnt-Out Case* (1960)

*Authors: Wendy Austin (PI), Paul Byrne (CoI), Brendan Leier (CoI), & E. Goble (CoI) - Funded by the Caritas Health Group, 2006-2007.*

Within health care, the relationship created between patient and caregiver shapes the moral space within which ethical action occurs. Without engagement patients are alone, no matter how many

professionals surround them. And professionals, without an empathic connection with patients, cannot fulfill their fiduciary promise to them.

Engagement, however, requires the intentional action of moving close to those in one's care. So one wonders what happens when this closeness is seen as a source of trauma to the caregiver? Can this engaged space, shared by professional and patient, be dangerous rather than safe?

Though originally used to describe reduced public empathy toward social problems and crises, in the early 90s, the term compassion fatigue became applied to a disengagement or lack of empathy emerging in the caregiving professions. It first appeared in a professional development article for nurses written by Carla Joinson (1992). Compassion fatigue was a type of burnout; nurses were “burned out and burned up” by caring for others (p. 116). Caring, empathy, and emotional investment were seen as costing the caregiver and putting health professionals at risk.

Compassion fatigue is considered to be caused by exposure to another's suffering, combined with one's own empathic response. It is equated with burnout, secondary traumatic stress disorder, vicarious traumatization, secondary victimization or co-victimization, secondary survival, compassion stress, emotional contagion, and counter transference. Charles Figley, a much-cited researcher, considers it equivalent to secondary traumatic stress disorder, a psychological disorder he describes as similar to post-traumatic stress disorder. He advises treatment.

Research to date, however, fails to capture fully the source of compassion fatigue and the personal, professional and organizational factors that influence its development. Stress management techniques do not suffice and strategies that merely lessen engagement have the potential to diminish ethical practice. The complexity of engagement in health care must be acknowledged and addressed with thoughtfulness and attentiveness to the everyday realities of health professionals.

Despite its ambiguity, health professionals find the term, compassion fatigue, compelling. These professionals are searching for words to name the frustration, fatigue, and distress they feel on the frontlines. Their feelings must not be dismissed. As researchers, policy makers, and healthcare professionals, we need to pay attention as the term

seems to capture something of a common experience. Perhaps it is the basic meaning of the words, compassion (with suffering) and fatigue (weariness) that calls to health professionals. It may be that compassion fatigue is what Bernard Williams (1985) terms “a thick concept,” one that embraces both fact and value, whose application is “determined by what the world is like” (p. 129), and which reveals social realities related to human interaction (Levering, 2002). Exploring the nature of compassion fatigue may help us to understand engagement and, in turn, how to practice ethically.

### **An Exploratory Study**

To this end, we are using relational ethics to explore how nurses define compassion fatigue and their experience of it within a hospital setting. We want to explore compassion fatigue as an experience closely linked to everyday practice and directly influenced by the healthcare environment. Though still in the recruitment phase of the project, compassion fatigue does not appear to be limited to one area of specialization or practice: nurse participants have come from various areas of hospital practice.

### **Implication for Practice**

Understanding compassion fatigue contributes to our understanding of engagement as essential to ethical practice and the supports required to foster it. This has implications for the wellbeing of professionals, the availability and retention as staff, and the maintenance of quality work environments in health services. Nurses, for example, lose more work time due to illness/ disability than any other group (Canadian Institute for Health Information, 2001), amounting to a loss of 17.7 million hours annually (CNA, 2006). Compassion fatigue may be a factor. Furthermore, compassion fatigue can directly motivate professionals to leave their place of employment and even their discipline. There are implications for patients, as well. A professional with compassion fatigue can place them at risk. Acknowledging and addressing compassion fatigue therefore is essential for ethical practice.

*References available upon request.*

# Factors Associated with the Retention of Hospital Privileges by Urban Physicians in Alberta

*Authors: Sheny Khera, MD, MPH<sup>1</sup>, Olga Szafran, MHSA<sup>1</sup>; Neil Bell, MD, MSc<sup>1,2</sup>; Lisa Steblecki, MD, MPH<sup>1</sup>; Rene Brownoff, MD<sup>1</sup>; Egbert Krikke, MD<sup>1</sup>. Department of Family Medicine<sup>1</sup> and Department of Public Health Sciences<sup>2</sup>, Faculty of Medicine, University of Alberta.*

There has been an exodus of family physicians from the hospital setting in spite of numerous studies that have shown that patient care is enhanced when a family physician is involved. There is relatively little information on the clinical, economic and administrative changes required in the hospital environment that would facilitate the retention of acute care hospital privileges by Canadian family physicians.

The objective of this research study was to identify the changes needed in the present primary health care environment that would encourage urban family physicians to retain their hospital privileges. Also, to examine whether urban family physicians have reduced the scope of their hospital privileges, what factors were associated with these decisions, and what would be needed to entice these physicians to broaden the scope of their privileges.

## Methods:

The study design was a self-administered mail out questionnaire. Study participants were family physicians/general practitioners who have active hospital privileges in acute care hospitals in urban Alberta in 2005. These urban centers were: Edmonton, Calgary, Grande Prairie, Medicine Hat, Fort McMurray, Red Deer & Lethbridge.

## Results:

426 family physicians responded to the questionnaire (54% response rate).

65.7% of family physicians limited the scope of their hospital privileges. The top three areas in



*Dr. Sheny Khera*

which hospital privileges were limited were: obstetrics (43.7%), emergency shifts (28.7%), and internal medicine (22.1%).

Of the 220 family physicians who have limited or planning to limit/give up privileges, the top 5 reasons were: (1) lifestyle (69.5%), (2) poor remuneration (55.9%), (3) no pay for on-call (42.7%), (4) increased office workload (38.2%), (5) increased patient acuity/complexity (35.9%).

The top five factors to maintain or re-broaden privileges were: (1) on-call pay (37.3%), (2) family physician skills/role understood/respected (37.1%), (3) Alternate Payment Plan (33.3%), (4) after hours coverage (32.4%), (5) free parking (30.0%). 41.3% of family physicians would not increase the scope of their current hospital privileges.

## Conclusion:

The main reasons for family physicians limiting/giving up hospital privileges include issues related to payment, lifestyle, patient complexity, and workload. Addressing economic factors (on-call pay, alternate payment plan for inpatient care), clinical factors (after hours coverage), and administrative factors (role & skills of family physicians understood/respected; free parking) may encourage family physicians to maintain or re-broaden their privileges.

**Acknowledgment:** This study was funded by a Janus Research Grant, CFPC.

# A Clinical Audit of Palliative Care Needs and Services Provided to Dying Patients in Institutional and Community Settings in Capital Health

*Authors: Konrad Fassbender, Robin Fainsinger, Dennie Hycha, Nicole Bonville, Karen MacMillan, Carleen Brenneis*

## Background

Palliative care is a relatively new discipline and is rapidly evolving. As a result, the objectives, limits and nature of palliative care are neither clearly defined nor unequivocally agreed upon. Nonetheless, guidelines and best practices need to be continually developed, even if the research evidence to guide clinical practice is limited. Clinical audit is one approach to quality assurance and has been defined as “the systematic critical analysis of the quality of health care”. Lack of time, expertise and validated tools have been identified as the most frequent barriers to conducting audit. In a desire to identify and implement opportunities for improvement, ALPACA (Alternate Level of Palliative and End of Life Care Audit Instrument) was developed to assess appropriateness of resource use and effectiveness of organizational structures. The purpose of this study therefore is to continue to develop and refine a clinical audit tool to evaluate appropriateness of care provided to patients at end of life, across both institutional and community settings.

## Objectives

1. To evaluate chart review as a method to describe the health care needs and resource use by palliative and end-of-life patients in the Capital Health Region.
2. To refine and validate ALPACA as an audit tool for the evaluation of appropriate resource utilization by palliative and end-of-life patients.
3. To describe the potential population for palliative care services:

## Approach

We abstracted data from the first three consecutive days (visits in community settings) to describe patient acuity and procedures for a single



*Dr. Konrad Fassbender*

point in time and to improve the likelihood of observing a full assessment and clinical plan. The items abstracted by the ALPACA tool include: age, gender, culture/ethnicity, language, education, income, diagnosis, advance directives, interdisciplinary care, morphine equivalent daily dose (MEDD), physician order changes, symptoms assessment, social work / psychological assessment, interdisciplinary progress notes, pressure ulcer risk assessment and nursing care. A total of 175 medical charts were selected from sites selected randomly from the patient population that has died between

January 1 and December 31, 2005 across six sites in Capital Health. Inclusion criteria consisted of: lengths of stay/care exceeding 3 days (or visits) in length, episode of care coded as medical (surgery, obstetrics and psychiatry are therefore excluded). All causes of death were considered. Data was abstracted using ALPACA and periodically reviewed by the investigators. ALPACA v2.3 is the product of this process and included three revisions. ALPACA v2.3 was converted to TELEFORM™ v9.0 format, which allows automated conversion of data entered with pen and paper to electronic format. The research nurses used pen and paper to enter the data into the forms. A research assistant entered this data into TELEFORM™ v9.0 format and converted the resulting database into SPSS™ v14.0 format for analysis. ALPACA results in the collection of 254 observations (variables) for each patient and three consecutive days (visits) of care. Data reduction (aggregation and averaging) was applied to convert this dataset to approximately 100 variables. A two-step cluster analysis was then used to assign patients to groups with similar profiles of resource utilization and need. A scoring algorithm then provides insight into the optimal number of clusters, cluster frequencies and descriptive statistics. Cluster frequencies and variable importance charts help to describe determinants of appropriateness and identify potential mismatched needs and care settings for patients at end-of-life. Although these are determined statistically, review of descriptive data and the use of subjective criteria by clinicians and program administrators help to establish the validity of the results. Ability to assess appropriateness however is limited to information recorded on charts. Standards differ across sites and for levels of appropriate care. Ethics and administrative approvals were granted for this study.

## Findings

A total of 175 patient charts were abstracted and represent six care settings and seven institutions or programs yielding a total of 501 days of observation. Of patients admitted to a facility, 52.8% were directly admitted from the home while a third were admitted from hospital. Median length of stay varied from 15.5 days for patients in acute settings to 430 days for patients in long term care facilities. Acute care patients also spent a significant time in emergency averaging 26.3 hours with a maximum of 104.3 hours. Average documentation rates for 25 core variables varied from 66.8% in palliative care settings to 43.0% in non-palliative care settings.

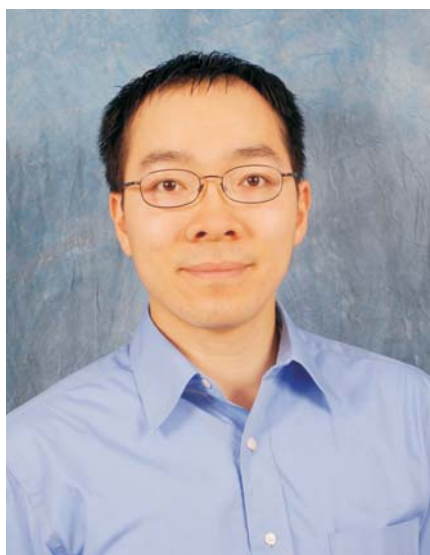
Approximately two-thirds of patient charts contained a DNR order, varying from 48% in long term care settings to 96% in tertiary care and hospices. Physician order changes varied from 0.52 per visit in palliative home care to 9.99 per day in acute settings. Opioid pain medications are most prevalent in tertiary care and lowest for patients in long-term care facilities. Physicians see patients about once every two days or visits across all settings (0.4 per day in palliative home care to 2.1 times per day in acute care). Respiratory, physical and occupational therapists see patients on average every ten days. Nursing care interventions (defined by a list of 13 procedures requiring intensive nursing resources) vary from 0.2 procedures during a palliative consult, to 0.9 procedures in long term care facilities to 3.8 in acute care. Long term care facility population describes an older female population while the tertiary care unit looks after a younger population with an average age of 64.9 years. The age of acute care patients average 77.5 years which is lower than the 84.6 years of long term care but much higher than tertiary care. Personal directives can be found in 8% of palliative consult records and 68% in long term care facility records. A total of 65.1 patients are being cared for on account of cancer. Palliative home care patients are characterized with higher functional status while patients in acute and hospice settings averaged lower scores. On average, patients in tertiary palliative care unit are more symptomatic while patients in long-term care facilities are less symptomatic. Two-step cluster analysis identified three cohorts: Group 1 or “Acute EOL” is homogenous and is comprised solely of acute care patients. Group 2 or the “chronic palliative care” group is comprised of all the long term care, most hospice patients plus some acute and tertiary care patients. Finally, group 3 or “Acute palliative care” group is comprised mainly of the tertiary unit and a handful of hospice patients.

## Limitation

Chart review is limited primarily by the reliance on documentation. Documentation rates may be understated in that some institutions and units include the use of temporary means of recording information and therefore not available to the abstractor at the time of review.

# Supported-Employment Program Processes and Outcomes: Experience of people with Schizophrenia

Article by K.W.David Liu, MSc, OT(C), OTR, is Occupational Therapist II, Department of Mental Health, Grey Nuns Community Hospital



*K.W. David Liu*

Most people with severe and persistent mental illness desire to have paid employment. Yet this cohort continues to experience a very high unemployment rate. It has been estimated that in Canada, the unemployment rate among people with mental illness was around 70 to 90%.

Recently researches have confirmed that pre-vocational training alone (i.e. lengthy work skills/habits training in a simulated environment) does not improve employment rate of people with mental illness. A supported employment model, on the other hand, began to generate more promising results. One distinct characteristic of the supported employment model is that it emphasizes the importance of first getting a paid employment and then receiving work skills training as well as on-going support at the job site.

A recent review on a number of related studies concluded that the supported employment model is about 2.5 times more effective than traditional

vocational rehabilitation models in helping people with mental illness to obtain paid employment in the open labour market. However, two questions arose: Why are program dropout rates high (40% or more)? And why do some participants stay in the programs although they do not gain employment for long periods of time? A qualitative study was conducted to explore what supported employment program participants perceived are the: (1) important program processes and outcomes, and (2) the conditions that influence those program processes and outcomes?

## Method

The study was based on the grounded theory approach and was reviewed and approved by the Health Research Ethics Board. Seven study-informants with schizophrenia were recruited from a supported employment agency. Table 1 shows their demographic information.

Gender	Female: 4	Male: 3
Employment status at time of study	Unemployed: 3	Employed: 4
Previous psychiatric admission	Yes: 6	No: 1
Age range	20 - 60 years	
Est. length of illness	2.5 - 22 years	
Time in the programs	4 - 17 months	

*Table 1. Demographic information of study-informants*

Data were collected through individual interviews. Each interview started with a key open-ended statement: "Tell me about your experience of participating in these supported employment programs." Data analysis process involved the three grounded theory steps: open, axial, and selective

coding. Figure 1 shows how study findings emerged.

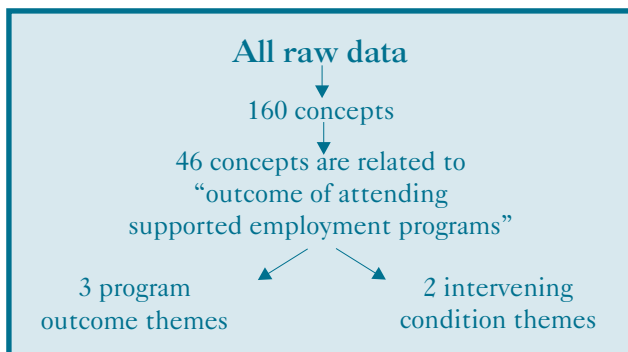


Figure 1

### Findings

Based on the program participants' perspective, a tentative theory was developed to explain the processes and outcomes of supported employment programs (Figure 2).

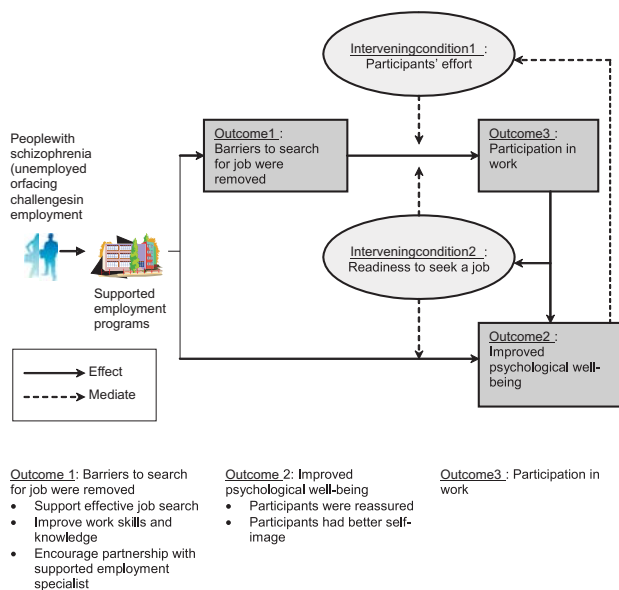


Figure 2: Supported employment processes and outcomes

### Implications to Practice

One interesting study finding is that obtaining employment is not perceived as a direct outcome of participating in supported employment programs. As illustrated in figure 2, obtaining employment is mediated by the program participants' personal preparedness (i.e. program participants' readiness and efforts in job seeking). In other words, despite excellent supported employment programs, participants who did not feel

ready for job seeking and who did not put in much effort were less successful in obtaining employment. Nevertheless a desire to have paid employment should still be the only criterion for supported employment programs referral. Clinicians or vocational specialists should adjust program strategies according to program participants' level of readiness in order to ultimately achieve better vocational outcomes. Readiness can be improved by informing potential program participants of their role and responsibilities in the supported employment programs. Also specially designed interventions should be available for program participants to become more aware of and to improve their own readiness.

### Implications to Program Evaluation

Although participation in work was cited as important, it is evident from study findings that “obtaining employment” is only one of the outcome indicators of supported employment programs' effectiveness. Program evaluators should consider incorporating other identified outcome indicators (i.e. participants' level of reassurance, self-image, effectiveness to seek a job, and quality of partnership between participants and the supported employment specialist, etc.). Also important is to measure “effort” and “readiness” to seek a job particularly for those participants who have not been successful in obtaining employment from the programs.

### Conclusion

Gain of employment alone is a limited indicator of the effectiveness of supported employment programs. Supported employment program participants can achieve meaningful outcomes even though they do not obtain employment immediately. This study highlights the importance of participation in meaningful occupations (“paid employment” in this study) as both a desired rehabilitation outcome and a therapeutic process. The identified supported employment processes provide an empirical foundation for enhancing supported employment practice and future research.

*This article is based on a published manuscript by the author: Liu, K.W.D., Hollis, V., Warren, S., & Williamson, D. L. (2007). Supported employment processes and outcomes: Experiences of people with schizophrenia. American Journal of Occupational Therapy, 61, 543-554. It was also presented as a poster in “From innovations to practice: The promise and challenge of achieving recovery for all” Conference held in Cambridge, Massachusetts, USA in April 2008. References available upon request.*

# Testicular Cancer Patient Participation in Tissue Banking: the Alberta Research Tumor Bank Experience

by Edith Pituskin, RN, Mn; John Danyluk, MD; George Wood, MD; Edie May, RN; Matthew Parliament, MD; Scott North, MD; Kathryn Calder, RN, MN(c); Sambasivarao Kamaraju, PhD.

## What is the 'Alberta Research Tumor Bank (ARTB)'?

With the direction of Dr John Danyluk and Dr Kelly Dabbs, fresh frozen tumor banking of breast cancer specimens was initiated in May 2001, originally called the 'PolyomX' Tumor Bank. With the processes and procedures they developed at the Misericordia site, tumor banking is now established at Edmonton area hospitals, with all types of cancer specimens considered for inclusion. Fresh frozen tumor banking is technically challenging and requires close coordination of activities (eligible patient, intra-operative review of the specimen, precise handling and identification procedures, specific storage requirements) as well as ongoing communication between team members (pre-admission clinic, surgeon and surgery staff, pathologist and ARTB bank staff). Tissue donors also provide a blood sample for the ARTB, and written consent allowing periodic review of their medical records and for use of their samples for research.



*Dr. John Danyluk*

## Why is tumor banking important?

A promising area of research is the identification of “biomarkers”, or genetic profiling that could be used to diagnose disease risk, presence of disease, or to tailor treatments for a disease in an individual. With cancer specimens, scientists hope to learn which people should receive treatment, which treatments would work the best, and exactly how much of the treatment the person should



*Edie May, RN*

receive. In this way, people would receive the exact amount and kind of anti-cancer treatment that would work best for them, avoiding unnecessary

treatments and side effects. Fresh frozen tumor specimens allow scientists to perform the highly sensitive testing methods necessary when undertaking genetic profiling research.

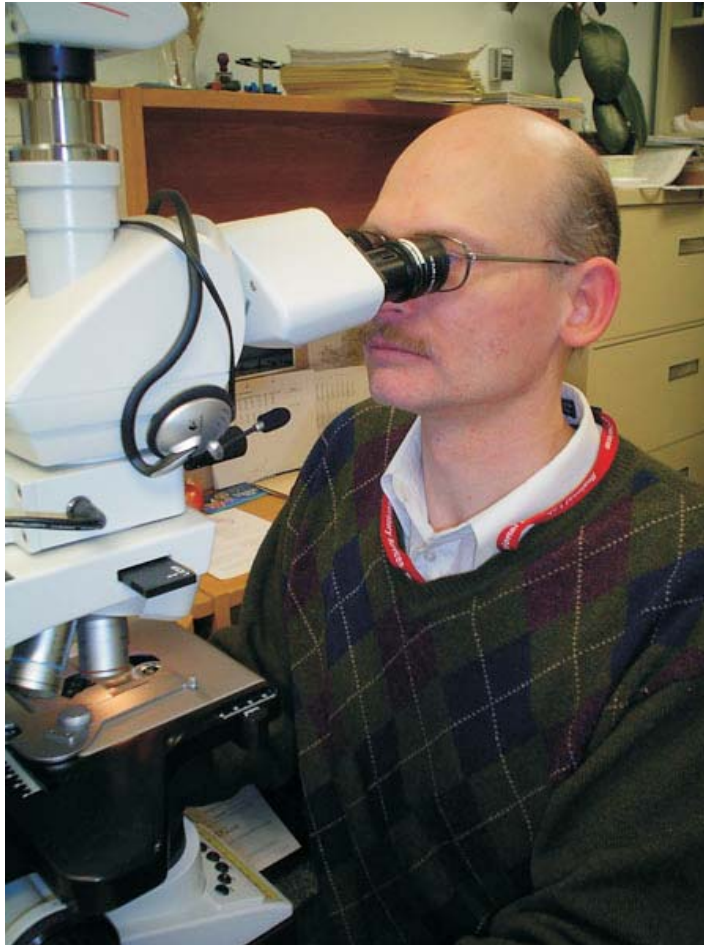
### Why bank testicular cancer specimens?

Testicular cancer incidence rates have significantly increased in Canada by 2.2% per year,

from 6.7 per 100,000 in 1983 to 9.6 per 100,000 in 1999. Other developed countries have reported similar incidence rates. Currently, there is no accepted explanation for these worldwide trends. Factors related to modern life are thought to contribute, such as sedentary lifestyle, childhood over-nutrition or early puberty. Exposures to various chemicals or toxins in the increasingly polluted environment are also concerning; future epidemiologic and biomarker research may explain the risks conveyed by these exposures.

The majority of testicular cancer patients are completely cured with the removal of the testicle alone; additional treatments are recommended for men believed to have higher risk of recurrence. While pathologic indicators such as larger tumor size and lymph-vascular invasion influence oncologists' opinions regarding the aggressiveness of a tumor, these indicators are not sufficiently reliable. Genetic

profiling offers great hope, with the potential to not only identify causes of cancer development, but also provide the ability to improve on pathologic characterization of tumors and assess risk of disease recurrence. Better understanding of testicular malignancies will assist in identifying those men who are truly at higher risk of recurrence.



*Dr. George Wood*

However, research has been limited worldwide by the scarcity of testicular tumors that are banked. This may be due in part to testicular cancer being a relatively uncommon malignancy, but is also due to the additional technical skills required to bank these specimens. These technical aspects were considered and resolved by Dr Danyluk and his colleagues prior to initiating testicular cancer banking in March 2007; 22 samples have since been collected. All men have expressed interest in having their specimen banked, provided written consent and contributed a blood sample to the ARTB. The rate of accrual of testicular cancer samples is higher than the accrual rate in two other tumor banks surveyed in Canada.

### What will happen in the future?

The higher-than-normal accrual rates of testicular cancer specimens in the ARTB will contribute to a significant number of samples. In order to undertake translational research projects in genetic profiling, large numbers of tumor samples are needed in order for genetic patterns to be recognized in a population. With ARTB research, we hope to learn how to identify which men might be at risk, which men should receive treatment, and what type and amount of treatment is needed for their particular kind of testicular cancer.

The Alberta Research Tumor Bank is supported by the Canadian Breast Cancer Foundation-Alberta/NWT and Prairies chapter.

# Caritas Nurse Scientist: Donna Wilson, RN, PhD

## Home Care and Chronic Illness

A research study was recently conducted using three years (2003/04, 2004/05, and 2005/06) of data provided by Alberta Health and Wellness to examine linkages between chronic illness and home care. This study found only a small share (<2%) of Albertans receive formal home care services each year now, which is interesting as approximately 10% of Albertans are hospitalized each year. Home care clients receive an average of 2 hours of home care each week. Another surprising finding is that there are fewer clients now each year as compared to the late 1990s and early 2000s. After the hospital cutbacks in the mid-1990s, the number of home care clients had increased each year until 2001 to being nearly 65,000. In 2005, there were only 61,000 Albertans who received home care. This reduction in home care accessibility could be a major factor in higher than expected hospital rates now and growing wait lists for hospital care, as home care clients are more often elderly, female, not married, living with someone, urban, and receiving a health care insurance premium subsidy. Most home care clients also had multiple diagnosed illnesses, and these ailments were extremely varied among the home care

clients. One of the main findings was that half of all clients were receiving home care for less than 3 months now and one half were needing home care on a long-term (3 months more) basis, a classification that indicates a state of chronic illness. Long-term clients were older, more often female, and more often from an urban health care region. These persons used 90% of all of the care hours provided each year by home care providers across Alberta. In conclusion, home care is a health care service that appears to be overlooked and disregarded as to its importance in sustaining chronically-ill persons in the community.



*Donna Wilson, RN, PhD*

If you have any questions, please contact your Caritas Nurse Scientist via [donna.wilson@ualberta.ca](mailto:donna.wilson@ualberta.ca)

## Acute Delirium Detection and Management Forum

Thursday, October 9th, 2008, 12:00-16:30 hrs at the Misericordia Community Hospital Auditorium

Luncheon & Refreshments will be provided

The nursing literature that exists to help nurses detect and help adults with acute delirium is mainly based on old care practices, with some insights about the cause and medical management that have been gained through research. Nursing care for patients experiencing acute delirium is not yet based on nursing research nor supported by current research-based evidence. Please come for a half day of discussions on detecting acute delirium, safeguarding patients who are experiencing acute delirium, and helping to shorten or stop the episode of acute delirium. Please come and share your insights and practices, as we work to develop a best-practice nursing standard of care.

**Pre-registration is required.** To register, please contact Mary-Ann Clarkes at the Caritas Research Centre, phone 780-735-2274 or via email at: [caritasresearch@caritas.cha.ab.ca](mailto:caritasresearch@caritas.cha.ab.ca)

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